DISCUSSING GOALS OF CARE:
Evidence based communication skills in action.

Abstract
Discussing goals of care and limitations of medical treatment with patients is a challenging task which faces all medical practitioners. This guide provides an overview of decision making and communication skills relev.

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PART 1. INTRODUCTION

We have hundreds of thousands of professional conversations with people throughout our working lives. Many of the people we see will be ill, or caring for someone who is ill, and will often be experiencing strong emotions.

There is now good evidence that the way in which we communicate can influence both physical and psychological health outcomes for patients, as well for health professionals. Patients and families rate health practitioners highly when they are able to communicate openly and discuss matters both good and bad with them. Communication is therefore a cornerstone skill for all medical practitioners.

Effective communication is a set of skills. It can be learned and practiced in the same way that we develop other skills in medicine such as suturing or paracentesis. The literature demonstrates that communication skills can be improved through understanding theory, mentored exposure to practice, repetition, feedback and reflection. This leads to increased confidence and satisfaction of health practitioners with reduced rates of stress and burnout. This workshop is based on these evidence based communication skills and training methods.

Discussing goals of care, limitations of medical treatment and resuscitation is a challenging aspect of clinical practice for all medical professionals. There is a consensus in the literature that people who are frail or have life limiting medical conditions want and should be provided with opportunities to discuss their future care and treatment preferences. However in practice this occurs only infrequently. Surveys of clinicians identify that a lack of confidence, skills and knowledge about how to initiate these conversations means they are often avoided or delayed. Clinicians describe that these conversations can be uncomfortable, challenging with difficulties including ascertaining patients’ preferences and deciding on the “right time” to raise such issues.

There is a growing body of literature around how to approach these challenging conversations. This workshop applies these practical evidence based skills in an experiential setting to provide participants with a safe learning environment in which to explore these skills. It is hoped that this workshop will enhance participants’ own “tool kit” of communication strategies to use when confronted by these challenging discussions in their ongoing medical career.

1.1 About this manual:

This manual provides an overview of the current literature around limitations of medical treatment and communication skills. In this manual we review core evidence-based approaches to discussing these issues with patient. We look at core skills for difficult conversations including dealing with mismatched expectations. It is hoped that this guide will provide participants with a “tool box” of communication skills which are relevant and practical for these difficult conversations. It is hoped that this guide will assist participants in their ongoing pursuit of quality communication and best practice patient care.
PART 2: BACKGROUND: Goals of care and clinical decision making

Discussing goals of care is a vital skill for all health care professionals caring for patients with life-limiting illnesses and their families. Being adequately informed is essential for such patients and their caregivers to participate in decisions about their treatment and care, to set priorities and to prepare for death. Clinicians need to be able to provide information regarding their current illness and its future impact on their health to enable patients and families to make appropriate decisions and adapt to the situation.

Discussing goals of care is difficult. The literature identifies a general mismatch in expectations and understanding around prognosis and end-of-life issues. For health professionals, these conversations can be challenging and uncomfortable. Reasons for this discomfort have included: lack of training and support, time pressure, fear or lack of confidence in responding to patients’ emotional responses, desire not to upset patients or their families, a feeling of hopelessness regarding the unavailability of future treatment options. There is, however, a consensus that for patients who are frail or have life-limiting illnesses it is important to provide opportunity to discuss goals of care.

While many health care professionals fear that introducing this topic will upset the patient and dispel any hope, evidence suggests that patients can engage in such discussions with minimal stress and maintain a sense of hope and empowerment even when the prognosis is poor. In addition, awareness of prognosis is associated with greater patient satisfaction and lower depression levels in patients.

It is hoped that this program will provide clinicians with the skills and confidence to approach these important discussions with patients.

2.1 A model for CPR decision-making.

It is generally accepted that goals of care decision-making is a shared process between clinician and patient. It involves a technical judgement about the patient’s illness and the expected response to treatment such as CPR and a discussion with the patient and/or surrogate decision maker that explores their values and beliefs around treatment. The nature and focus of the discussion will depend on the combination of these factors.

One identified model of decision making around CPR (but may also be substituted for other treatments) uses the technical analysis of the success of CPR (would this patient survive CPR) to focus the aims of the discussion with that patient (see Figure 1). A decision about CPR or other medical treatments can only be understood within the context of the patient’s overall medical condition and management. Hence a discussion about CPR needs to be part of a bigger discussion about the person’s overall health and not in isolation.
These four patient categories can provide a guide to direct the goals and approach to goals of care discussions with the patient. Category 1 and 2 include patients where a medical judgement has been made that CPR can neither prolong life nor provide greater comfort. CPR would not be of benefit and may do harm to these individuals by denying the patient a gentle dying. Offering a non-beneficial treatment is not respectful of patient autonomy and, by law, medical practitioners are not obliged to offer medically futile treatments. However, it is likely that the patient or family may expect CPR is attempted. We know that understanding of CPR outcomes is generally poor in the general population. It is therefore important to have a CPR-related discussion so there are no harmful misunderstandings. The patient’s autonomy is respected by explaining why CPR would not be appropriate.

Patient’s in the third category whom may survive CPR but with a poor outcome the clinician focuses on discussing why CPR may or may not be in the best interest of that person due to the poor chance of surviving unimpaired and what the best and worst case scenarios following CPR attempt would be. This allows the patient to consider each outcome in the context of their wishes and beliefs. For instance some will view that life should always be preserved where possible even if the quality of poor. Whereas others would not wish to survive if their function was limited.

Further information on this model of decision making is provided in the included reading:

PART 3: EVIDENCE BASED COMMUNICATION SKILLS

In this section we review core evidence based communication skills and how these apply to goals of care conversations with our patients.

Understanding the theory of how doctors and patients communicate with each other can help us develop and apply communication skills in practice. A core aspect of communication theories is the recognition that all participants bring with them their unique perspectives, experiences, knowledge, emotions and goals to each conversation. Both the clinician and the patient have their own goals in any communication encounter, which may or may not match up. Evidence has shown that if we do not seek to understand (and show them with understand through empathy) where patient is coming from and what is important to them, then we will not be able to meet their needs for trust, support and understanding. Adopting this ‘patient-centred’ approach has been shown to result in effective and efficient communication with our patients.

3.1 Key communication skills

There are a number of core communication skills identified in the literature which facilitate effective and efficient communication with our patients. These skills are often used unconsciously by skilled communicators but can also be employed consciously during difficult conversations or to improve communication skills. This workshop provides an opportunity for you to practice and experience these skills in a realistic clinical simulation.

Three of the most strongly supported skills are:

1. ‘Ask – Tell – Ask’

Ascertaining a person’s understanding or viewpoint before imparting information and checking out understanding afterwards.

2. ‘Tell me more’

Exploring further so that you have a good understanding

3. Responding to emotion - NURSE

Using the acronym NURSE for tools to assist empathic responses.

We will now consider these skills in detail.

1. “Ask – Tell – Ask”

This is a simple and effective strategy which allows the clinician to quickly establish a patient’s prior knowledge and understanding. Education theory has shown us that learning happens most effectively when it take into account what the learner already knows and builds on this. In the clinical encounter this allows you quickly to gauge their understanding of their illness. Further, by asking you first you start with the patient’s perception and agenda which immediately validates and shows you are willing to listen. This begins to develop rapport and engender trust.
Ask the patient what their understanding of their situation is.

“Can you tell me what your understanding of your illness is?”

“What have the doctors said about how your ... is?”

Tell them in plain language what you need to communicate: what the results are, what the treatment options are, best case and worst case scenario.

“It sounds like it might be helpful if I explained why your breathing has been getting so much worse lately. Would that be ok?”

Note: asking permission to share information shows respect for the patient and changes the dynamic.

Ask the patient about their understanding now. Use this as an opportunity to assess what has been taken in. This may also lead to other concerns that can be addressed. Encouraging the patient to relay the information assists them to consolidate what you have said, similar to learning something, it sinks in better if you had to explain it to someone else.

“I imagine your children might ask you about what we discussed, how would you explain this to them?”

2. ‘Tell me more’

Sometimes it might not be entirely clear what a patient is saying or feeling or what information they need from you. Clarifying this can pinpoint the true concern or agenda for a patient. It also conveys to the patient that you really want to understand their perspective and allows them to feel heard.

For example, a patient saying “I just don’t want to do this anymore” might lead to the perception that the patient wishes to stop all treatment and is ready to die. Responding with “Tell me more” might lead instead to “I am sick of hospitals and tablets and just want to be well again” perhaps they are not ready to die but expressing their frustration with being unwell. This gives you a much clearer understanding of what the concerns are and how to respond appropriately.

It is also a useful technique to use when you are not sure of where to go next in a conversation. Sometimes in a conversation if you feel stuck, it can be because of a mismatch in goals and perceptions between clinician and patient. Exploring the patient’s thoughts often provides you with a direction or window through which to take the conversation. Try “tell me more” when you don’t know what else to say and see where it leads.

3. Responding to emotion: Empathy and ‘NURSE”

Communication involves an interplay between cognitive aspects (knowledge, facts and information) and emotions. When strong emotions are present they usually take over making it difficult to retain or process information. You may have experienced this yourself when anxious or stressed you often forget what you were doing or lose your car keys. In a clinical conversation we usually want the patient to listen to some information we have to share. This is difficult if they are struggling with an emotional reaction. Acknowledging an emotion not only shows that you understand but can allow the patient space to process their emotional reaction. This may allow them to move from an emotional space to a cognitive space where they can take in a process information. It may be for this reason that consultations have shown to be quicker (and more effective) when a clinical employs these skills.
The idea is to think about “accepting” that an emotion is present rather than feeling that you need to fix it or solve the problem. Often it is not possible to fix the emotion: you cannot change how unwell the person is and many of these problems cannot be solved. Simply knowing that someone has heard and accepted their feelings is comforting and certainly supportive. Acceptance is not the same as agreement. You can accept that a person feels that way even if you do not agree with their view.

Empathy involves listening carefully and then communicating an understanding of what the person is feeling. Studies have shown that even clinicians believe they are behaving empathetically these cues are often missed by patients unless this is made explicit.

The acronym NURSE represents techniques that can be used to respond emotions and express empathy. They are options or “tools” to be used at appropriate times rather than a prescription for empathy.

N = Naming the emotion
U = Understanding
R = respecting and reassuring
S = Silence and support
E = Exploring

N: Naming

Identifying the emotion that is present is an important first step in responding empathically. It can also be useful to identify or acknowledge the emotion in your conversation with the patient. This can be a way of demonstrating your understanding but also to allow the patient to reflect on their reaction and perhaps to uncover the concerns which underlie it. If you are not sure what the emotion is you can always ask:

“I can’t imagine how it must feel to hear all this...”

NOTE: It is important to suggest rather than declare the emotion; people don’t usually like being told how they should feel.

“It sounds like you have been worrying about your health lately, how are you feeling about it?”

“I can see this is hard, how are you feeling about it?”

U: Understanding.

By listening carefully you can identify the core messages the person is communicating. Give yourself time to reflect and respond. Once you feel you have identified the core message, summarising can be a useful tool to check with the patient that you have understood them correctly. This ensures that you have got it and also allows the patient to clearly see that you have been listening and are interested in what they have to say.

“So, if I’ve understood you correctly, the thing which has been really hard for you, is that you haven’t been able to spend as much time with your family and you feel bad that you haven’t been able to help your daughter with the kids. Is that right?”

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R: Respect and reassuring.

You can show respect non-verbally through posture and facial expressions. A verbal response is helpful because it clearly tells the patient their emotions and opinions are being understood and are important. Showing respect can be difficult as it needs to be genuine to be believed and avoid being “cheesy”. Consider matching this with the level of emotional response

Some examples of respect:

“‘I really admire the way you have faced...’”

“I can see how much you love your family”

“It is amazing how you have continued to keep going after everything you’ve been through, what helps get you through?”

Reassurance can be a powerful form of comfort and support. However, it is important to avoid premature reassurance. Reassurance is best targeted once you are sure you have fully understood the patients concerns. If you have missed this it may block the patient from expressing the issues which are most worrying them. Once you are sure you have understood what the patient is saying you can provide reassurance which is meaningful and targeted, therefore it often accompanies summarising, for instance:

“It sounds as if you are really worried about the pain and you are worried that it will just continue to get worse until the end. Is that correct?... well that is a really common concern, but it is really very unlikely. Would it be helpful to talk about what else we can do if the pain becomes more troublesome?”

S: Support.

Health professionals, particularly physicians, are seen as an important source of support for patients with serious illnesses. Clinicians can show support in many ways, such as expressing sadness that the patient is suffering, expressing a willingness to help and making statements about partnership. Many patients with life threatening illnesses, particularly in the context of discussions about limitations of treatment, fear they will be/are being abandoned when “there is nothing more we can do”. Making statement, if truthful, that you will be there to care for them can be helpful.

“Although we cannot fix your lungs, there is still a lot we can do to help you”

“Our team will be there to support you, no matter what happens”

E: Exploring.

The most effective empathy can help the patient to reflect and extend their own understanding of their situation. Often asking questions to aid your understanding and showing that you are interested in more than superficial issues will also allow the patient to clarify their own deeper thoughts about the issue.

“It would help me to learn more about...”

“I sense that things aren’t easy for you right now. Could you tell me more about what makes this time difficult for you?”
3.2 “PREPARED” guidelines for discussing prognosis and end of life issues with patients.

Accompanying this manual you will find a copy of “Clinical practice guidelines for communication prognosis and end-of-life issues with adults in the advanced stages of a life-threatening illness, and their care givers” by Clayton et al published in the MJA 2007. This document provides a guide for how to initiate and conduct conversations about end-of-life care issues. The communication skills outlined above can form part of the delivery of this framework. This clinical practice guideline provides suggested phrases to use in these difficult conversations and is an excellent resource in preparing for the challenging task of discussing goals of care.

Below we summarise the key aspects of the PREPARED framework;

**P**

*Prepare for the discussion:*
- Confirm the diagnosis/prognosis and investigation results before initiating conversation.
- Try to ensure privacy and uninterrupted time for discussion.
- Negotiate who should be present during the conversation (i.e. do other family members need to be there).

**R**

*Relate to the person*
- Develop rapport
- Show empathy, care and compassion during the entire consultation

**E**

*Elicit patient and caregiver understanding and information preferences:*
- Identify the reasons for this consultation and elicit the patient’s expectations.
- Clarify the patient’s understanding of the situation
- Establish how much detail and what they want to know
- Consider cultural and contextual factors influencing information preferences
  (The ‘Ask’ of Ask-Tell-Ask)

**P**

*Provide Information* tailored to the individual needs:
- Offer to discuss what to expect in a sensitive manner giving the patient the option not to discuss it
- Pace information according to their information preferences, understanding and circumstances.
- Use clear, jargon-free, understandable language
- Explain the uncertainty, limitations and unreliability of prognostic and end-of-life information.
- Avoid being too exact with timeframes

**A**

*Acknowledge emotions and concerns:*
- Explore and acknowledge the patient’s emotional response to the discussion
- Explore fears and concerns
- Respond to the patient’s distress during the discussion
  (Remember NURSE and tell me more)

**R**

*Realistic hope:*
- Be honest without being hurtful or blunt or giving more detailed information than desired by the patient.
**Discussing Goals of Care**

- Do not give misleading of false information to try to protect to reassure the patient.
- Provide appropriate reassurance that support and appropriate treatments will continue.
- Remember to avoid premature reassurance and to target your response to the patient’s concerns.
- Explore and facilitate realistic goals and wishes.

**E Encourage questions and discussion:**

Encourage questions and information clarification; be prepared to repeat explanations.
Check understanding of what has been discussed and if the information provided meets the patient’s needs.
Leave the door open for topics to be discussed again in the future.

**D Document:**

Write a summary of what has been discussed and who was present in the medical record.
Speak or write to other key health care providers involved in the patient’s care including the patient’s general practitioner.

From ‘Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness and their caregivers.’ Clayton, JM; Hancock, KM; Butow, PN; Tatersall, MHN: Currow, D. MJA 2007: 186(12)

The full version of these guidelines can also be downloaded for free from:

**3.3 A note on discussing CPR**

Prior to opening a conversation with a patient that will lead to decision making about CPR consider whether the discussion is necessary or appropriate.

Remember the general principles outlined in this manual, including PREPARED acronym and the importance of exploring and responding to emotions.

**Uncover the big picture first: discuss CPR in context, not isolation.**

Start with a general discussion around the patient’s values and expectations about the future with regard to their health, their views on prognosis and goals of care if their health should deteriorate.
Do not go straight for their wishes about CPR. Remember “ask-tell-ask”.

“What is your understanding of what is happening to your health at the moment?”

“Can you tell me how you see the future with respect to your illness?”

When discussing goals of care in the context of the broader picture of the person’s illness, this will usually focus the discussion on the relevant treatment decisions to be made such as the use of non-invasive ventilation or antibiotics over CPR. It allows the person to reflect on their illness and therefore place this decision making in the context of their illness. You can explore their concerns and anxieties about getting sicker and allows you to provide reassurance with regard to the treatments that you can still offer.

**Do not give a choice if resuscitation is medically inappropriate.**
If CPR is judged to be clinically inappropriate by senior medical staff or the treating team do not ask the patient ‘what do you want when your heart stops’ as this creates an inappropriate burden of choice. This can be perceived by patients/families that they are making the decision between living and dying. If there is no choice then do not offer it. You would not offer to chop someone’s foot off to cure their lung cancer, it wouldn’t work, so why offer CPR if it won’t work.

Studies have shown that general population have unrealistic expectations of the outcomes of resuscitation (too many TV medical dramas?). Further, they show that when presented by the facts about resuscitation this does change their decision making.

**Reaffirm your support, focus on what you can do not what you can’t.**

Patient’s often fear being abandoned or not treat at all simply because they are “NFR”. Remember to focus your conversation on the treatments that you can offer such as antibiotics or symptom management. Ensure they know they won’t be given up on and will continue to receive the best possible care.

“Not giving CPR does not mean we are giving up on you. On the contrary, we will continue to be extremely active and supportive in our care. It simply means that when death does come, our focus will be on keeping you comfortable and dignified rather than prolonging the dying process”.

**If a specific conversation about CPR is required:**

Clarify the patients understanding about CPR.

If a patient has a misinformed view of the reality of CPR success, ask them if they would like to know more about CPR, THEN provide them with facts.

Keep explanations simple, unless they request specific details.

Describe CPR in the context of the patient’s goals, not in isolation, with reference to their values, wishes and beliefs.

*I wish* statements can be a powerful way of aligning yourself to the patient’s wishes, through acknowledging their desires whilst conveying the reality:

“I wish that CPR would give you what you want”

“It’s not choice you or I have made, it’s what is happening to your body. I wish that CPR could change that”.

**Respond to emotion.**

This is the essence of all communication.

**Clearly document discussions and outcomes.**

Completed the appropriate goals of care/limitations of medical treatment paperwork. Also remember to document your discussion and who was present in the notes.

3.4 Dealing with mismatched expectations
This section considers conversations where patients’ and families’ expectations for treatment options and illness outcomes are different to those of the treating team. This can be one of the most challenging scenarios when discussing goals of care.

Dealing with mismatched expectations in a goals of care conversation is one of the most challenging encounters in clinical practice. This scenario often leads to fear or avoidance and can raise strong emotional reactions in our patients AND ourselves. Not addressing these issues can lead to escalation of the mismatch, with worsening doctor-patient relationships, decision making which lacks consensus/support, and ultimately the possibility of worse outcomes for the patient and increases chance of complaint.

However we can employ communication skills to respond to these challenges. Handled well it can lead to greater understanding by all involved and be a mechanism through which important concerns and problems can be openly discussed and addressed.

Reasons for mismatch expectations include:

- Information/facts: absent, not understood, conflicting, misheard or misinterpreted.
- Strong emotion: excess stress, fear, anxiety
- Fixed firm beliefs: e.g. religious or cultural norms
- Mistrust
- False or redundant hope
- Denial: a coping mechanism to maintain a positive outlook in order to protect oneself against the impact of the medical evidence to the contrary.

Where mismatch is present, using a patient-centred approach can be particularly effective in helping patients and family members feel respected and understood. Patients who feel they have had an opportunity to be listened to, and believe their key concerns are being taken seriously and respectfully may be more prepared to discuss the underlying troubling issues more openly and with less potential for ongoing escalation of conflict.

Clinicians and patients bring to each conversation their own beliefs, assumptions and emotions which underpin their reasoning and wishes. If we are convinced we are right and the other person is wrong and then seek to persuade them otherwise, escalation of emotions often arise. Understanding there are two valid cognitive and accompanying emotional aspects to a potential mismatch is fundamental to addressing it appropriately. Understanding and acknowledging a different perspective is not the same as endorsing it, yet it can make the difference to a successful outcome. Trying to understand rather than convince is the key here.

A structured approach to mismatched expectations using PREPARED framework:

1. Explore the person’s understanding of their situation and why they believe what they do (Elicit patient understanding)
   
   “It would really help me if you could tell me your understanding of where things are up to with your treatment and what is likely to happen with your illness”

   “Tell me what others are telling you about what is going on right now”

2. Consider using a hypothetical question to explore goals further (Elicit patient understanding)
“while we are hoping that things go well with your treatment, if by some chance you didn’t get better, what would be the most important things to you”

3. Check for “windows” in which to gently probe or challenge unrealistic beliefs (Elicit patient understanding)

“I can see you really want to get better and I would like that too. Are there ever times when you have worries that things are not going so well?... Can you tell me what is on your mind during those times?”

“Your goals is to get stronger, and we’ve just discussed how you are spending more time in bed. What do you think is happening?”

4. Explore and respond to emotions

Explore and respond to emotions that may be behind the person’s mismatched expectations – using NURSE or tell me more.

“I can’t imagine how frustrating this is for you.”

“I wish things were different...”

5. If there is misinformation offer to discuss your understanding of the situation (Invitation/knowledge)

“I can hear that you’re concerned that taking morphine might make life shorter. Would it help if I explained a little more about morphine and what affect it has on length of life?”

6. Aim for common ground on which to base solution (strategy and summary).

Some other tools that can help you in a difficult conversation.

And not but:

Compare the two ways of saying the same thing. Which one helps to de-escalate the mismatch?

“I can see that homeopathy is really important to you for your pain but I think the morphine would also help too.”

VS

“I can see that homeopathy is really important to you for your pain and I think the morphine would also help too.”

‘But’ tends to negate any statement that is said before it and make it less valid. ‘And’ on the other hand supports and builds on the previous statement. It is far more constructive rather than destructive therefore demonstrating respect for the other perspective.

“I wish...” statements
‘I wish’ statements are a powerful way to show alignment of the doctor with the desires of the patients, whilst acknowledging the realistic likelihood of achieving those desires.

“I wish I could be sure that the antibiotics are going to help this time. If they don’t work like we hope have you thought about what might happen?”

“Hoping for the best, preparing for the worst”

This is similar to the I wish statement in that you focus on what you are both hoping for (aligning) and on the other hand allowing the patient to contemplate what may happen if it doesn’t go well.

“We are all hoping for the best. If that wasn’t to happen and you continued to get sicker, would it be useful to talk about plan B?”

If the mismatch persists…

In the face of absolute denial do not force the person to confront their situation or prognosis otherwise it may increase distress. Consider referral for second opinion and remember you can’t win everyone over.

If the patient doesn’t want to talk about the future then don’t push it. Leave the option open that should they want to talk about it in the future, that’s ok.

“It’s not easy talking about this stuff. That’s fine. If there does come a time when it would be useful to talk more, please let us know.”
References


2. **Would you like to talk about your future treatment options? Discussing the transition from curative cancer treatments to palliative care.** Schofield, P, et al. 2006, Palliative Medicine, Vol. 20, pp. 397-406.


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